

# Early Community-Based Service Utilization and Its Effects on Institutionalization in Dementia Caregiving

Joseph E. Gaugler, PhD,<sup>1</sup> Robert L. Kane, MD,<sup>2</sup>  
Rosalie A. Kane, PhD,<sup>2</sup> and Robert Newcomer, PhD<sup>3</sup>

**Purpose:** The present study attempts to determine whether utilizing community-based long-term-care services early in the dementia caregiving career delays time to nursing home placement (adjusting for severity of dementia). **Design and Methods:** With a reliance on data from 4,761 dementia caregivers recruited from eight catchment areas in the United States and followed over a 3-year period, a Cox proportional hazards model was conducted that considered key components of the stress process (e.g., context of care, primary objective and subjective stressors, and resources), duration, and community-based long-term-care use. **Results:** An analysis of interaction terms in the Cox regression model found that those individuals who utilized in-home help services earlier in their dementia caregiving careers were more likely to delay institutionalization. **Implications:** The findings suggest the practical importance and cost-effectiveness implications of early community-based service use, and they emphasize the role of timing when one is conceptualizing the proliferation of stress in the dementia caregiving career.

**Key Words:** *Community-based long-term-care use, Dementia, Caregiving*

The financial and psychosocial costs of nursing home placement for older adults have offered strong motivation for policymakers, practitioners, and researchers to search for service modalities that delay, if not prevent outright, disabled older adults' institutionalization. Foremost among these options are community-based long-term-care services, such as adult day programs or in-home help services (e.g., chore, personal care, or companion services). One challenge that appears particularly problematic is that families tend to utilize community-based long-term care late in their caregiving "careers." This may negate the potential benefits of adult day or in-home help services to provide respite and possibly delay nursing home placement (Zarit, Stephens, Townsend, Greene, & Leitsch, 1999). Our objective in the present study was to determine whether community-based long-term-care utilization earlier in the dementia caregiving career would operate to delay institutionalization.

## *Community-Based Long-Term Care and Its Effects in Dementia Caregiving*

Several multiregional and national demonstrations have evaluated expanded, publicly subsidized, community-based long-term-care services that were designed to delay or prevent institutionalization of disabled older adults. From the early 1980s to more recent efforts, it has generally been acknowledged that the provision of community-based long-term care to impaired older adults and their informal caregivers has mixed or no effects in delaying nursing home placement (e.g., Gaugler & Zarit, 2001; Hedrick et al., 1993; Miller, Newcomer, & Fox, 1999; Weissert, Cready, & Pawelak, 1988; Weissert & Hedrick, 1994). Issues from liberal targeting to low service utilization by caregivers seem to have attenuated the effectiveness of community-based long-term care. Evaluations of community-based long-term care among cognitively impaired older adults and their caregiving families

---

This research was supported by a New Investigator Research Grant (NIRG-2249) from the Alzheimer's Association to Dr. Gaugler and a contract (509-89-0069) from the Health Care Financing Administration to Dr. Newcomer.

Address correspondence to Joseph E. Gaugler, PhD, Assistant Professor, The College of Medicine, Department of Behavioral Science, 110 College of Medicine Office Building, Lexington, KY 40536-0086. E-mail: jgaugle@uky.edu

<sup>1</sup>Department of Behavioral Science, The University of Kentucky, Lexington.

<sup>2</sup>Division of Health Services Research and Policy, University of Minnesota School of Public Health, Minneapolis.

<sup>3</sup>Department of Social and Behavioral Science and Institute for Health and Aging, University of California-San Francisco.

have also been conducted. Similar to earlier evaluations, findings on the effectiveness or efficacy of community-based long-term-care programs on outcomes such as caregiver stress, depression, and time to nursing home placement have been mixed (Gaugler & Zarit; Gottlieb & Johnson, 2000; Miller et al.). Of those evaluations that did show significant effects, most utilized small samples, had design intervals of 1 year or less, and implemented quasi-experimental designs in which participants were not randomly assigned to a treatment or control condition, thus increasing threats to internal validity.

An examination of the characteristics of dementia caregivers who utilized community-based long-term care offers possible insights as to why adult day programs or in-home care services did not yield significant benefits. Studies have shown that 22% to 50% of dementia caregivers refused community-based long-term-care services (Biegel, Bass, Schulz, & Morycz, 1993; Brody, Saperstein, & Lawton, 1989; Cox, 1997; Montgomery & Borgatta, 1989). Those who did not utilize community-based long-term-care services had concerns about relinquishing care to a stranger; reported that respite was not needed; and had greater anxiety than users. In contrast, community-based long-term-care users appeared more likely to care for relatives suffering from severe cognitive and functional deficits and also experienced greater distress (e.g., Adler, Kuskowski, & Mortimer, 1995; Caserta, Lund, Wright, & Redurn, 1987; Cox, 1997). Similar efforts have found that many families provided assistance to cognitively impaired relatives from 3 to 4 years prior to community-based long-term-care service use (Cox, 1997; Zarit, Stephens, Townsend, & Greene, 1998).

Some evidence suggests that community-based long-term-care utilization earlier in the dementia caregiving career may yield more substantial benefits for cognitively impaired older adults and their family caregivers. For example, the key predictors of early nursing home placement in dementia are care recipient problem behaviors and caregiver stress, which often supercede the effects of activity of daily living (ADL) dependency (e.g., Fisher & Lieberman, 1999; Gaugler, Kane, Kane, Clay, & Newcomer, 2003). Interestingly, longitudinal analyses have found that behavior problems do not necessarily increase during the course of dementia, but instead appear to move forward in the earlier or moderate stages of the disease and recede in the later stages of dementia (e.g., Aneshensel, Pearlin, Mullan, Zarit, & Whitlach, 1995). In addition, emerging research has begun to analyze the long-term challenges facing those individuals who have recently assumed dementia care responsibilities. Although few studies exist in this area, the findings imply that, in contrast to wear-and-tear conceptualizations of adaptation (in which caregiver stress and other negative outcomes become exacerbated over time; see Townsend, Noelker, Deimling, & Bass, 1989), those individuals

in the earlier stages of caregiving may expedite institutionalization (Gaugler, Kane, Kane, Newcomer, & Clay, 2005) and experience increased stress and depression in both general (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003) and dementia-specific (Gaugler, Zarit, & Pearlin, 2003) informal care contexts. To some extent, the descriptive findings potentially support the need to deliver community-based long-term-care services that provide respite earlier in the dementia caregiving career, as the demands and events that occur soon after caregiving onset may precipitate early institutionalization or other outcomes. Utilizing longitudinal data from the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE), we test the hypothesis that dementia caregivers who use more community-based long-term-care services earlier in their caregiving careers are more likely to delay nursing home placement of their care recipients.

### *Research Focus*

Evaluations of community-based long-term-care services for dementia-specific samples suggest that delayed utilization may attenuate these services' potential to influence nursing home placement (e.g., Gaugler & Zarit, 2001; Gottlieb & Johnson, 2000; Zarit et al., 1999). However, to our knowledge, no study to date has examined whether community-based long-term-care use early in the dementia caregiving career influences key outcomes such as institutionalization. Partially because of the use of smaller samples that included informal caregivers of varying duration, prior research has not had the statistical power necessary to determine whether dementia caregivers who assumed care responsibilities more recently and used community-based long-term-care services were more likely to avoid institutionalization for their care recipients. To address these limitations, we utilized data from a 3-year prospective study that recruited dementia caregivers from eight catchment communities in the United States (Rochester, NY; Urbana, IL; Memphis, TN; Portland, OR; Cincinnati, OH; Parkersburg, WV; Minneapolis, MN; and Miami, FL) in the current study. If dementia caregivers who utilize services earlier are more likely to delay institutionalization, then community-based long-term-care programs could be effectively targeted and delivered to families to address this key outcome. Moreover, the results may suggest the importance of timing when researchers are analyzing dementia caregiving outcomes in both descriptive and intervention studies.

Several conceptual frameworks have been developed to explain the manifestation of negative outcomes in dementia caregiving. For example, the stress process model (e.g., Aneshensel et al., 1995) provides a multidimensional framework for analyzing informal caregivers and time to institutionalization among older adults suffering from dementia.

Model components include background and socio-demographic characteristics of the caregiver and care recipient (context of care), care demands that potentially affect caregiver outcomes (e.g., primary objective stressors, such as ADL dependencies and cognitive impairment), and primary subjective stressors, or caregivers' emotional appraisals of care demands. The stress process model considers variables that potentially alleviate negative aspects of dementia caregiving, such as assistance provided by other family members or friends (resources). The model also includes global caregiving outcomes, such as depression, that are a result of the accumulation of primary stress. The stress process model has demonstrated considerable utility in the study of time to nursing home placement in dementia caregiving (Gaugler et al., 2003), and the subsequent analysis adopted this framework when examining the effects of community-based long-term-care utilization.

## Methods

### Procedure

The MADDE was a 3-year, multiregional analysis of expanded case management for family caregivers of individuals suffering from Alzheimer's disease or related disorders. Case management was the basis of MADDE, as case managers assessed the need of caregivers and care recipients and initiated care plans that included a range of community-based services largely reimbursed by Medicare (for additional detail on MADDE service delivery and content, see Newcomer, Yordi, DuNah, Fox, & Wilkinson, 1999). With the exception of Medicaid participants, clients and their caregivers paid a 20% copayment for any demonstration service to instill a sense of cost consciousness. The following criteria governed participants' inclusion in MADDE: all older adults (a) had a physician-certified diagnosis of an irreversible dementia, (b) were enrolled or eligible for Parts A and B of Medicare, (c) had service needs, and (d) resided at home in one of the eight aforementioned MADDE catchment areas. The caregiver was defined as the relative who provided the most assistance to the person with dementia throughout the course of MADDE. MADDE implemented an experimental research design, with care recipients randomly assigned to either a treatment group eligible for the expanded Medicare case management benefit or a control group that did not receive the benefit. The sites served older adults with dementia and their caregiving families from December 1989 to November 1994. Individuals with dementia (i.e., care recipients) enrolled in the study over a 2-year period, and caregivers were administered in-person interviews by trained nurses and social workers every 6 months over 3 years. Baseline was considered to be the MADDE enrollment date.

The principal analysis of MADDE indicated that the expanded Medicare benefit had no effect on time to nursing home placement for care recipients (Miller et al., 1999). For this reason, we included both the treatment and control conditions from MADDE in the present study to maximize sample size.

### Sample

We initially considered 5,311 care recipients and their primary caregivers who completed a baseline interview. However, information on duration of care was collected at the first interview subsequent to baseline and then throughout the study. For this reason, we did not include care recipients who died or were institutionalized during the 6-month interval between baseline and Time 2 of MADDE ( $n = 550$ ) in subsequent analyses. This step resulted in a preliminary sample of 4,761 primary caregivers and their care recipients at baseline. In general, non-responders tended to report greater impairment in care-recipient cognition, function, and behavior, as well as greater burden, depression, and unmet need ( $p < .05$ ). For detailed bivariate comparisons between caregivers who provided duration of care data in MADDE and those who did not, please contact J. Gaugler.

### Measures

Table 1 presents key descriptive baseline information for the sample.

**Institutionalization.**—MADDE considered institutionalization dates for stays that the caregiver reported as permanent. Those stays initially paid for by Medicare that ended in death (rather than discharge to the community) were also classified as permanent stays. Nursing home entry dates for short stays (i.e., less than 60 days) were gathered, but these stays were not counted as permanent nursing home days. The establishment of data quality in MADDE and the corroboration of caregiver reports with demonstration-financed reimbursement claims were successful (Newcomer et al., 1999). By the conclusion of the 3-year study period, 2,185 care recipients (45.9%) had been institutionalized. Among those care recipients who were institutionalized, the average length of time in the study was 473.44 days ( $SD = 238.44$ ; range = 31.00–1094.00).

**Community-Based Service Utilization.**—To measure service utilization, interviewers provided primary caregivers with a fixed set of options during each interview and asked them to identify the services they had used in the past 6 months and how often they relied on these services. Service utilization was based on total number of hours or days used during the 6 months prior to each

Table 1. Descriptive Baseline Information (N = 4,761)

Variable	Value
Community-based LTC service use	
In-home help hours: past 6 months (i.e., sum of personal, chore, and companion services)	
M	90.23
SD	232.02
Adult day services: days used in past 6 months	
M	7.69
SD	24.22
Context of care	
Site (%)	
Florida	14.7
Illinois	12.0
Minnesota	17.5
New York	11.1
Ohio	12.3
Oregon	12.7
Tennessee	12.2
West Virginia	7.5
Gender (female; %)	59.3
Race of care recipient (Caucasian; %)	88.1
Age of care recipient	
M	78.53
SD	8.00
Care recipient Medicaid eligible at any interview (%)	30.3
Care recipient lived with caregiver (%)	74.7
Caregiver gender (female; %)	73.0
Caregiver relationship to care recipient (spouse: %)	49.7
Caregiver age	
M	62.63
SD	14.25
Caregiver income <sup>a</sup>	
M	5.63
SD	2.90
Caregiver education <sup>b</sup>	
M	3.56
SD	1.37
Duration of care (in months)	
M	48.08
SD	48.86
Caregiver employment status (employed %)	33.6
In treatment group of MADDE	50.8
Primary objective stressors	
Behavior problems	
M	9.17
SD	4.06
Care recipient ADL dependencies	
M	3.75
SD	2.79
Care recipient IADL dependencies	
M	6.47
SD	1.73
MMSE score	
M	15.45
SD	8.61

Table 1. (Continued)

Variable	Value
Primary caregiving hours: typical week	
M	88.09
SD	58.16
Sum of unmet needs w/ ADL and IADL care	
M	3.36
SD	3.92
Primary subjective stressors	
Burden	
M	12.54
SD	6.37
Resources	
Secondary caregiving hours: typical week	
M	13.33
SD	25.54
Global well-being	
Depression	
M	4.32
SD	3.30
Caregiver ADL dependencies	
M	0.24
SD	0.67
Caregiver IADL dependencies	
M	0.77
SD	1.49
Negative subjective health rating <sup>c</sup>	
M	3.05
SD	0.78

Notes: ADL = activities of daily living; IADL = instrumental ADL; MADDE = Medicare Alzheimer's Disease Demonstration Evaluation; LTC = long-term care; MMSE = Mini-Mental State Examination.

<sup>a</sup>1 = under \$4,999; 11 = \$55,000 and above.

<sup>b</sup>0 = no formal schooling; 1 = elementary school; 2 = some high school, 3 = high school; 4 = some college; 5 = college graduate; 6 = postgraduate.

<sup>c</sup>4 = poor; 3 = fair; 2 = good; 1 = excellent.

assessment. Caregivers could generally identify the number of times such services were used and provide a percentage distribution of these units into applicable service types. When this procedure could not distinguish between types of services, the reported units were distributed equally among the applicable services. Efforts were made in the original MADDE analyses to ensure that services were not double counted.

We include two types of community-based services in these analyses, that is, in-home help (sum of chore, personal care, and companion services) and adult day services, because these services accounted for 80% of community-based long-term-care use in the MADDE samples (Newcomer et al., 1999). We measured service units in hours for in-home help and in days for adult day care. Comparisons of self-reported service use with demonstration-reimbursed claims in the MADDE



analyses found that 93% of the individuals could correctly identify that they were not receiving a service (e.g., personal care services; Miller et al., 1999). Although the reporting of actual service units was less reliable, we found no systematic bias in such reports. Community service variables were treated as time-varying covariates in subsequent models.

Consistent with other community-based long-term-care research in dementia caregiving, a considerable proportion of the individuals in the sample did not utilize adult day services during the course of MADDE. For example, 21.3% of the individuals ( $n = 1,014$ ) did not use in-home help prior to institutionalization or the conclusion of MADDE. In contrast, 62.7% of all caregivers or care recipients ( $n = 2,986$ ) did not utilize adult day services during MADDE.

**Context of Care.**—Care-recipient demographic variables included site, gender, race, age, Medicaid status, living arrangement, and whether the care recipient was assigned to the MADDE treatment or control group. Caregiver demographics included gender, caregiver relationship to the care recipient, age, income, employment status, and education.

**Primary Objective Stressors.**—Functional and cognitive status variables included care-recipient dependence on 10 ADL tasks (Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963; baseline  $\alpha = .89$ ) and 8 instrumental ADL (IADL) tasks (Lawton & Brody, 1969; baseline  $\alpha = .89$ ). We assessed behavior problems such as asking repetitive questions, being suspicious or accusative, or wandering or getting lost with a 19-item measure (Zarit, Orr, & Zarit, 1985; responses are 0 = no and 1 = yes; baseline  $\alpha = .93$ ). Case managers administered the 19-item Mini-Mental State Examination (MMSE) at Time 1 only (Folstein, Folstein, & McHugh, 1975; baseline  $\alpha = .95$ ). We assessed the number of hours caregivers typically spent managing care recipients' functional and cognitive needs. We also summed caregivers' unmet needs with care recipients' ADL and IADL limitations (i.e., not enough help indicated by the caregiver; baseline  $\alpha = .79$ ).

**Primary Subjective Stressors.**—We measured caregiver burden by using the seven-item version of the Zarit Burden Scale (Zarit, Todd, & Zarit, 1986; baseline  $\alpha = .87$ ).

**Resources.**—We measured secondary caregiving hours by having interviewers ask respondents how many hours per week they typically received help from other family members or friends.

**Global Well-Being.**—We measured caregiver depression with the 15-item Geriatric Depression Scale (Yesavage, Rink, Rose, & Aday, 1983; baseline  $\alpha = .98$ ). We also included caregivers' ADL and IADL

dependencies (baseline  $\alpha = .84$ ;  $\alpha = .75$ , respectively), as well as a single-item self-rating of health (item responses included 1 = poor, 2 = fair, 3 = good, and 4 = excellent), as measures of global caregiver functioning.

## Analysis

To capitalize on the 3 years of data available in the MADDE study design, we conducted an event-history analysis. An event-history analysis (also called survival analysis or hazards modeling) examines whether a particular event occurs (i.e., institutionalization) and, if so, when. We used a specific type of event-history analysis, a Cox proportional hazards model, to analyze the empirical effects of timing of community-based service utilization on institutionalization while we controlled for key stress process covariates. Specifically, the Cox model included the time-varying (i.e., those measures administered at each time point of MADDE, such as resources and primary stressors with the exception of the MMSE) and time-invariant stress process covariates (i.e., context of care indicators). In addition, we included the baseline duration of care and time-varying measures of adult day service use and in-home help utilization. To test the main study hypothesis, we created interaction terms that included duration of care and time-varying measures of adult day service use and in-home help utilization. Of secondary interest in the analysis was the interaction of community-based long-term-care utilization and other key dimensions of the stress process that could expedite nursing home placement; therefore, we included a series of interactions between adult day service use, in-home help utilization, and time-varying measures of primary objective and subjective stressors and in the Cox model. In this manner, we examined the potential moderating effects of community-based long-term-care use on not only duration of care but also other potential predictors of placement.

## Results

Before we conducted the Cox regression model, we conducted bivariate analyses between all covariates (e.g., community-based long-term-care use, context of care indicators, primary objective and subjective stressors, resources, and global well-being variables). Results showed that, although there were a number of significant associations between covariates (the greatest correlation was between time-varying ADL and IADL dependencies, at  $r = .62$ ,  $p < .001$ ), all of these associations fell below recommended rules of thumb of collinearity (i.e.,  $r \geq .75$ ; see Tabachnick & Fidell, 1996). In most instances, the significance of the bivariate analyses may have been due as much to the very large sample size as to any conceptually relevant relationships that

**Table 2. Cox Proportional Hazards Model: Caregiving Duration, Community-Based LTC Use, and Time to Institutionalization (N = 4,761)**

Predictor	$\beta$	SE	Exp( $\beta$ )
Context of care			
Site <sup>a</sup>			
Illinois	.90***	.10	2.45
Minnesota	.89***	.10	2.44
New York	.72**	.11	2.05
Ohio	.93**	.10	2.53
Oregon	.37**	.12	1.45
Tennessee	.37**	.11	1.45
West Virginia	.33**	.13	1.45
Caregiver was in treatment condition	-.02	.05	0.98
Care recipient gender (female)	-.31***	.07	0.73
Race of care recipient (Caucasian)	.68***	.09	1.97
Age of care recipient	.01***	.00	1.01
Care recipient Medicaid eligible	.90***	.05	2.46
Care recipient lived with caregiver	-.25***	.07	0.78
Caregiver gender (female)	-.24***	.07	0.79
Caregiver is spouse	-.15	.10	0.86
Caregiver age	.02***	.00	1.02
Caregiver income	.06***	.01	1.06
Caregiver education	.00	.02	1.00
Caregiver is employed	-.03	.06	0.97
Duration of caregiving	-.27***	.05	0.76
Primary objective stressors			
Care recipient ADLs (TV)	-.02	.02	0.98
Care recipient IADLs (TV)	-.12**	.04	0.89
MMSE score	.02***	.01	1.02
Behavior problems (TV)	.03**	.01	1.03
Primary caregiving hours (TV)	.00	.00	1.00
Sum of unmet needs (TV)	.03**	.01	1.03
Primary subjective stressors			
Burden (TV)	.02**	.01	1.02
Resources			
Secondary caregiving hours (TV)	.00	.00	1.00
Global Well-Being			
Depression (TV)	-.01	.01	1.00
Caregiver ADL dependencies (TV)	-.05	.04	0.95
Caregiver IADL dependencies (TV)	.05**	.02	1.06
Negative subjective health rating (TV)	.00	.03	1.00
Community-Based Service Use			
Adult day services (TV)	-.32**	.12	0.73
In-home help (TV)	-.18*	.08	0.83
Interactions			
Adult day services $\times$ Duration	.01	.02	1.01
In-home help $\times$ Duration	.03**	.01	1.03
Adult day services $\times$ Behavior problems	.00	.00	1.00
In-home help $\times$ Behavior problems	.00	.00	1.00
Adult day services $\times$ ADLs	.00	.01	1.00
In-home help $\times$ ADLs	-.01*	.01	0.99
Adult day services $\times$ IADLs	.04*	.02	1.04
In-home help $\times$ IADLs	.00	.00	1.00
Adult day services $\times$ MMSE	.00	.00	1.00
In-home help $\times$ MMSE	-.01*	.00	0.99

**Table 2. (Continued)**

Predictor	$\beta$	SE	Exp( $\beta$ )
Adult day services $\times$ Unmet need	.00	.00	1.00
In-home help $\times$ Unmet need	.00	.00	1.00
Adult day services $\times$ Burden	.00	.00	1.00
In-home help $\times$ Burden	.00	.00	1.00

Notes: ADLs = activities of daily living; IADLs = instrumental ADLs; LTC = long-term care; MMSE = Mini-Mental State Examination; TV = time-varying covariate.

<sup>a</sup>Florida is the reference category.

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

would have influenced the analysis of community-based long-term-care use and duration of care on time to institutionalization.

Table 2 presents the results of the Cox regression model and the effects of interactions between community-based long-term-care utilization and duration of care. A significant interaction occurred between in-home help utilization during the 3-year course of MADDE and duration of care ( $\beta = .03$ ,  $SE = .01$ ,  $\exp \beta = 1.03$ ,  $p = .01$ ). As Table 2 illustrates, when in-home help was not utilized during the course of MADDE, caregivers of more recent duration ( $\beta = -.27$ ,  $SE = .05$ ,  $\exp \beta = .78$ ,  $p < .001$ ) were more likely to expedite institutionalization than those in the later stages of their caregiving career. In this manner, the Cox regression provided partial support for our study hypothesis.

In addition to the main interaction, the Cox regression revealed several other significant interactions between community-based long-term-care use, caregiver stressors, and time to nursing home placement. The interactions between time-varying measures of care-recipient IADL dependencies and in-home help use ( $\beta = .02$ ,  $SE = .01$ ,  $\exp \beta = 1.02$ ,  $p < .05$ ) and adult day service utilization ( $\beta = .04$ ,  $SE = .02$ ,  $\exp \beta = 1.04$ ,  $p < .05$ ) were significant. Interestingly, when we interpreted the moderational effects of community-based long-term-care use on IADL dependence and time to nursing home placement, it appeared as though when no community-based long-term care was utilized, care recipients with fewer IADL dependencies were more likely to expedite institutionalization ( $\beta = -.12$ ,  $SE = .04$ ,  $\exp \beta = .89$ ,  $p < .01$ ). We also found that a significant interaction evident between baseline MMSE score, ADL dependencies, and in-home help utilization ( $\beta = -.01$ ,  $SE = .01$ ,  $\exp \beta = .99$ ,  $p < .01$ ;  $\beta = -.01$ ,  $SE = .01$ ,  $\exp \beta = .99$ ,  $p < .01$ ; respectively). Our interpretation of the direct MMSE effect suggested that, when in-home help services were not utilized, care recipients with a lower MMSE score were more likely to be institutionalized sooner ( $\beta = .02$ ,  $SE = .01$ ,  $\exp \beta = 1.02$ ,  $p < .001$ ).

## Discussion

Several limitations of this analysis are important to consider. Caregivers and dementia patients were

not randomly sampled and are not representative of the population, although the sample size and multiregional design is large for a study of dementia caregivers. Care recipients who were institutionalized or died during the first 6 months of MADDE were unavailable for analysis, because we measured duration of care only at the 6-month interval and beyond. Incorporating these individuals may have provided greater emphasis on the importance of community-based long-term-care utilization among recent caregivers. In contrast to other retrospective analyses that have utilized multiple indices of caregiving onset (e.g., Gaugler, Zarit et al., 2003), our study relied solely on the duration of care measure, potentially exacerbating recall error (e.g., participants may have reported a longer duration of care than that which actually transpired). In addition, duration of care as assessed in MADDE did not discriminate between levels of caregiving responsibility at onset. As a consequence of the retrospective design of the study, there was no way of determining the frequency of community-based long-term-care use that existed in the earlier stages of care for those who had begun providing informal help for more than 12 months.

Another important factor to consider when one is interpreting the findings is the low utilization of adult day services. On average, caregivers utilized 7.69 days of adult day services in the 6 months prior to baseline, and 62.7% did not use adult day care at all during the course of MADDE. As has been reiterated in evaluations of adult day services and its effectiveness for care-recipient and caregiver outcomes, a potential reason for the lack of demonstrable benefits is low utilization (Lawton, Brody, & Saperstein, 1989; Montgomery & Borgatta, 1989; Zarit et al., 1998). Because of the infrequent use of adult day services, these programs may have had little opportunity to exert benefits. The same process may have occurred in the current study, explaining the lack of effects of early adult day service utilization on time to nursing home placement.

The results suggested that, for caregivers in their earlier stages of the role, the utilization of in-home services such as personal care or chore help was predictive of a delay in institutionalization. Although a range of evaluations has suggested the equivocal effects of community-based long-term-care use in delaying nursing home placement, these studies have not considered the importance of timing, or when services are utilized in the course of dementia caregiving (e.g., Adler et al., 1995; Caserta et al., 1987; Cox, 1997). As the findings imply, the timing of service use is a potentially important component to consider when one is examining the empirical associations between community-based long-term care and key dementia caregiving outcomes. It is possible that, when in-home services are used earlier, dementia caregivers are offered the opportunity to acclimate to the range of care demands posed by the

cognitively impaired care recipient while receiving assistance. Caregivers may have time to implement plans and routines that can help them effectively respond to the normal care demands that occur. In-home help may also provide a sense of comfort, advice, and socioemotional support to the recent caregiver who is beginning to cope with a loved one's cognitive and functional decline. As prior research suggests, the circumstances surrounding the early phases of informal caregiving appear to have long-term implications on key outcomes (e.g., Burton et al., 2003; Gaugler, Zarit, et al., 2003). The empirical results build on this work by demonstrating that early community-based long-term-care utilization in the dementia caregiving context can potentially mitigate the upheaval that occurs during the early stages of informal long-term care and even delay nursing home placement, an elusive yet desired program outcome for community-based long-term-care providers.

The findings also present a more complex explanatory model. It was not clear whether those who indicated a need for community-based long-term-care services early in their dementia caregiving careers received the necessary formal help. As in other studies, adult day care utilization was low, suggesting some unwillingness on the part of dementia caregivers to utilize this service. The mechanisms determining need for community-based long-term-care services in the various stages of dementia care and whether the utilization of these services resulted in the alleviation of some unmet need were also unclear. In some instances, community-based long-term care may have been accessed in order to address pressing care issues (e.g., inflexible work hours), whereas in other situations community-based long-term-care services could have been used as a matter of convenience. For example, although caregivers who experienced greater burden were likely to expedite institutionalization (see Gaugler et al., 2003), the interaction model did not demonstrate that adult day service or in-home help utilization moderated the effect of this relationship. Although there was some evidence that in-home services moderated the relationship between primary objective stressors such as ADL dependencies and cognitive impairment, these effects were generally small. It is possible that the provision of in-home help may offer care recipients slight improvements in cognitive and functional dependence, leading to small delays in placement. In keeping with the stress process model, the moderational effects of in-home help on cognitive declines may then result in decreased burden (particularly in the earlier phases of dementia caregiving). Complex quantitative designs as well as qualitative research may contribute to a greater understanding of the process of service utilization and how formal help is linked to institutionalization during the various phases of dementia caregiving.

Contrary to our hypothesis, adult day service use and duration of care did not interact to influence time to nursing home placement. Unlike in-home help, which at its most flexible can be effectively integrated into families' care plans and directly targeted to meet specific care needs of older adults, adult day services tend to provide group based, standardized activities that may not be tailored to different family care needs (Gaugler & Zarit, 2001). Furthermore, in contrast to in-home help, caregivers who utilize adult day programs often have the added responsibility of preparing the care recipient for attending adult day services and, in some instances, transporting the care recipient to and from these programs (Berry, Zarit, & Rabatin, 1991). Another potential barrier to adult day service and community-based long-term-care use in general is cost. Caregivers who had to pay for such services (in the current sample, 1,633 dementia caregivers were part of the original MADDE control group and not eligible for Medicaid) may have delayed utilization for longer periods of time, making it more difficult for such services to exert demonstrable effects on nursing home placement (e.g., Gottlieb & Johnson, 2000; Zarit et al., 1998). Post hoc analyses that examined interactions between duration of care, adult day service use, and in-home help within the subgroup of 1,633 potential private-pay caregivers yielded results that were parallel to the main findings (i.e., those who utilized in-home services earlier in the dementia caregiving career delayed institutionalization). These initial results suggest that, although Medicaid may offer greater access to adult day service use or in-home help, Medicaid eligibility did not appear to have a considerable effect on the timing of community-based long-term-care use and nursing home placement.

It is important to note that although the timing of adult day service utilization did not influence nursing home placement, the empirical results do emphasize the potential effects of adult day programs in delaying institutionalization. Although prior research suggests that relinquishing care to out-of-home respite services may actually expedite the institutionalization process by increasing families' comfort in transferring daily care responsibilities to formal service providers (e.g., Gaugler, Jarrott, et al., 2003; Zarit et al., 1999), these so-called facilitating effects were not apparent in our current findings. Preliminary main effects models showed that greater adult day service use during the course of MADDE was associated with delayed institutionalization ( $\beta = -.32$ ,  $SE = .12$ ,  $\exp \beta = .73$ ,  $p < .01$ ). There may be several reasons for this pattern of findings; unlike in-home help, where there is more flexibility on the part of family to shape the delivery of the service to meet informal care needs, adult day services largely provide programs and activities geared toward dementia patients in the moderate to later stages of the disease, and they offer less adaptation toward

caregiver needs (e.g., flexible hours, individually tailored service content; see Gaugler & Zarit, 2001). Nonetheless, if utilized (and, as already indicated, overall utilization in the sample was relatively infrequent), the findings here suggest that the respite or time off offered to dementia caregivers through adult day service use could delay nursing home placement regardless of timing.

The findings have important implications for service targeting and delivery to family caregivers and individuals suffering from dementia. The study provides some of the first empirical support for a recommendation that is reiterated throughout community-based long-term-care evaluations: For particular types of services, earlier use during the course of dementia caregiving is likely to exert more benefit than if community-based long-term-care utilization is delayed (e.g., Gaugler & Zarit, 2001; Gottlieb & Johnson, 2000). The results are particularly important because the outcome of interest is one that has key public policy implications but has remained difficult to influence with community-based long-term-care implementation. Although there appears to be reluctance among dementia caregivers to utilize community-based long-term-care programs, descriptive research has demonstrated that the early stages of care provision may be among the most important when one is considering subsequent outcomes (Burton et al., 2003; Gaugler et al., in press; Gaugler, Zarit, et al., 2003). Developing delivery and targeting mechanisms within existing community service frameworks to ensure the earliest availability and flexibility of community-based long-term-care services may assist dementia caregivers to delay institutionalization. There is some concern that providing community-based long-term-care services earlier during the course of chronic caregiving may negate cost effectiveness, as more services are targeted to individuals who may utilize them for longer periods of time. Given the resource limitations that guide the funding of health care provision, the findings here suggest that, instead of offering extensive services as a tertiary benefit unlikely to reverse or delay the trajectory toward institutionalization, adopting a preventive strategy so that caregivers can adapt to the challenges of dementia care earlier may result in a more cost-effective approach to community-based long-term care for chronic disease in the elderly population, at least for in-home services (Smyer & Gatz, 1987; Weissert & Hedrick, 1994).

The findings of this study also reveal the varying effects of different community-based long-term-care approaches. Although in-home help services may or may not provide respite (e.g., even with in-home care help, it is possible that the family caregiver's day is still consumed with various care demands), it is possible that their flexibility in meeting the needs of individuals suffering from dementia can help those in the earlier stages of caregiving who may still be



establishing their own care plans and routines. Formal in-home care provision during the potentially tumultuous early stages of dementia caregiving may offer the assistance, support, and possibly even the guidance necessary to delay institutionalization. In contrast, stand-alone adult day services may not be as flexible in providing individually tailored care to families at different points in the dementia caregiving career, although the respite these services provide may still delay nursing home placement. The findings here yield insight on how different community-based long-term-care services may have variable effects throughout the dementia caregiving career, and offer guidance for how, when, and what community-based long-term-care services are most effective in delaying nursing home placement.

The results also emphasize important conceptual and methodological issues related to the longitudinal analysis of dementia caregiving outcomes. The findings suggest the potential effects of service utilization early in the dementia caregiving career; however, few studies examine the importance of timing for community-based long-term-care service use or other events that may have long-term implications for families and their elderly relatives with dementia. Longitudinal caregiving research has yielded comprehensive models of caregiving adaptation that take into account how stress proliferates from care responsibilities to other life domains that influence global outcomes (e.g., Aneshensel et al., 1995). However, contextual and life-course issues that occur at different points of dementia caregiving have yet to receive similar attention. Such refinements to the stress process would add considerably to our dynamic conceptualizations of dementia caregiving over time.

## References

- Adler, G., Kuskowski, M. A., & Mortimer, J. (1995). Respite use in dementia patients. *Clinical Gerontologist*, 15, 17–30.
- Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego: Academic Press.
- Berry, G. L., Zarit, S. H., & Rabatin, V. X. (1991). Caregiver activity on respite and nonrespite days: A comparison of two service approaches. *The Gerontologist*, 31, 830–835.
- Biegel, D. E., Bass, D. M., Schulz, R., & Morycz, R. (1993). Predictors of in-home and out-of-home service use by family caregivers of Alzheimer's disease patients. *Journal of Aging and Health*, 5, 419–438.
- Brody, E., Saperstein, A. R., & Lawton, M. P. (1989). A multi-service respite program for caregivers of Alzheimer's patients. *Journal of Gerontological Social Work*, 14, 41–74.
- Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist*, 43, 230–241.
- Caserta, M. S., Lund, D. A., Wright, S. D., & Redburn, D. E. (1987). Caregivers to dementia patients: The utilization of community services. *The Gerontologist*, 27, 209–214.
- Cox, C. (1997). Findings from a statewide program of respite care: A comparison of service users, stoppers, and nonusers. *The Gerontologist*, 37, 511–517.
- Fisher, L., & Lieberman, M. A. (1999). A longitudinal study of predictors of nursing home placement for patients with dementia: The contribution of family characteristics. *The Gerontologist*, 39, 677–686.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). Mini-Mental State: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189–198.
- Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (2003). Respite for dementia caregivers: The effects of adult day service on caregiving hours and care demands. *International Psychogeriatrics*, 15, 37–58.
- Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2003). Predicting institutionalization of cognitively impaired older people: Utilizing dynamic predictors of change. *The Gerontologist*, 43, 219–229.
- Gaugler, J. E., Kane, R. L., Kane, R. A., Clay, T., & Newcomer, R. (2005). The effects of duration of caregiving on institutionalization. *The Gerontologist*, 45, 78–89.
- Gaugler, J. E., & Zarit, S. H. (2001). The effectiveness of adult day services for disabled older people. *Journal of Aging and Social Policy*, 12, 23–47.
- Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (2003). The onset of dementia caregiving and its longitudinal implications. *Psychology and Aging*, 18, 171–180.
- Gottlieb, B. H., & Johnson, J. (2000). Respite programs for caregivers of persons with dementia: A review with practice implications. *Journal of Aging and Mental Health*, 4, 119–129.
- Hedrick, S. C., Rothman, M. L., Chapko, M., Ehreth, J., Diehr, P., Inui, T. S., et al. (1993). Summary and discussion of methods and results of the Adult Day Health Care Evaluation Study. *Medical Care*, 31, SS94–SS103.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffee, M. W. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *Journal of the American Medical Association*, 185, 914–919.
- Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, 9, 179–186.
- Lawton, M. P., Brody, E. M., & Saperstein, A. R. (1989). A controlled study of respite service for caregivers of Alzheimer's patients. *The Gerontologist*, 29, 8–16.
- Miller, R., Newcomer, R., & Fox, P. (1999). Effects of the Medicare Alzheimer's Disease Demonstration Evaluation on nursing home entry. *Health Services Research*, 34, 691–714.
- Montgomery, R. J. V., & Borgatta, E. F. (1989). The effectiveness of alternative support strategies on family caregiving. *The Gerontologist*, 29, 457–464.
- Newcomer, R., Yordi, C., DuNah, R., Fox, P., & Wilkinson, A. (1999). Effects of the Medicare Alzheimer's Disease Demonstration on caregiver burden and depression. *Health Services Research*, 34, 669–689.
- Smyer, M. A., & Gatz, M. (1987). Intervention research approaches. *Research on Aging*, 8, 536–555.
- Tabachnick, B. G., & Fidell, L. S. (1996). *Using multivariate statistics* (3rd ed.). New York: HarperCollins.
- Townsend, A., Noelker, L., Deimling, G., & Bass, D. (1989). Longitudinal impact of interhousehold caregiving on adult children's mental health. *Psychology and Aging*, 4, 393–401.
- Weissert, W. G., Cready, C. M., & Pawelak, J. E. (1988). The past and future of home- and community-based long-term care. *The Milbank Quarterly*, 66, 309–388.
- Weissert, W. G., & Hedrick, S. C. (1994). Lessons learned from research on effects of community-based long-term care. *Journal of the American Geriatrics Society*, 42, 348–353.
- Yesavage, J. T., Rink, T., Rose, T., & Aday, M. (1983). Geriatric Depression Rating scale: Comparison with self-report and psychiatric rating scales. In T. Crook, S. Ferris, & R. Bartus (Eds.), *Assessment in geriatric psychopharmacology* (pp. 153–167). New Canaan, CT: Mark Powley and Associates.
- Zarit, S. H., Orr, N., & Zarit, J. (1985). Understanding the stress of caregivers: Planning an intervention. In S. H. Zarit, N. Orr, & J. Zarit (Eds.), *Hidden victims of Alzheimer's disease: Families under stress* (pp. 69–86). New York: New York University Press.
- Zarit, H., Stephens, M. A. P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology: Social Sciences*, 53B, S267–S278.
- Zarit, S. H., Todd, P. A., & Zarit, J. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, 26, 260–266.
- Zarit, S. H., Townsend, A., Greene, R., & Leitsch, S. A. (1999). Patterns of adult day service use by family caregivers: A comparison of brief versus sustained use. *Family Relations*, 48, 355–361.

Received February 9, 2004

Accepted August 17, 2004

Decision Editor: Linda S. Noelker, PhD